

Loving nurse cares for society's downtrodden, forgotten HIV, AIDS children get love they desperately need

By Marian Wright Edelman
Special to Sentinel-Voice

It's inspiring to meet someone with the energy, passion and dedication of Nancy Granados, a pediatric nurse practitioner at the Hospital for Sick Children in Washington, D.C.

Granados cares for chronically ill infants and children, including many who are HIV positive or who have AIDS. She is not only their caregiver, but their advocate and sometimes the only family they have: In her ward are several children from weeks-old to 4-years-old who have never left the hospital.

They would be able to go home if they had families who could be trained to care for their special needs.

Many of Granados' "children" do go home, with parents, foster parents or grandparents. Sometimes that's a problem.

"I want to stress that these mothers love their children just as much as any mothers do," she said. "But a lot of these moms are just kids themselves and subject to many of the ravages of society's poor. Sometimes they're school dropouts, often they acquire AIDS because they abuse drugs, and now they're too sick to take care of themselves, let alone a medically needy

infant.

"And like the teens they are, they have typical adolescent behavior," she said. "They make promises. But then they get home and they get distracted, or sick, or back to using drugs, and they don't follow through."

In the best circumstances, mothers who can't care for their babies are persuaded to turn them over to foster care, visiting them when they are able.

"Then we have the second big problem," Granados said. There aren't enough foster families who will take HIV positive or AIDS babies.

Social stigmatization and fear of disease transmission stop many would-be parents from adopting, despite no case of inter-household AIDS transmission, ever being reported. Granados said one family was kicked out of their church when the congregation found out that they had adopted a baby who had AIDS and a grandmother (who is not HIV positive) took her grandchild when her daughter died of AIDS, but at a great price: Her other children now refuse to visit her home or have anything to do with her or the child.

"These are children," Granados cried.

"Children, who just happen to have a disease that society is mad at, or afraid of. When are we as a society going to get over these prejudices?"

Children born with vertically transmitted AIDS — they got the disease in the womb from their HIV-infected mothers — are living longer than they used to because of the new treatments available. Granados knows a 16-year-old born with the disease. She said new therapies might help children live longer.

"This is great news, but it's a wake-up call too," she said. "These are human lives forming. We are not supposed to be an orphanage. We are supposed to be a hospital. We are not supposed to be raising these kids. But we are. They end up staying because there is no place for them to go. We have kids who spend their whole lives at this hospital."

Volunteers are needed to be with these children, holding them, reading to them, rocking them, tutoring them and loving them, Granados said.

Sometimes these children find good homes with the older parents, but that's not always the best solution either. Granados recalled a 75-year-old woman who is trying to find someone willing to care temporarily for her great

grandchild when she goes to have cataract surgery.

"The burden is awesome. Everything has become warped in today's world. Somebody should be taking care of grandma, not the other way around," she said.

What can you do? Granados suggested volunteering at your local hospitals, becoming a buddy to a family in crisis, taking the caregiver and child to doctors' appointments, going grocery shopping, or baby-sitting when the caregiver is sick. You can donate money and time to the few centers that care for these babies.

"Everyone is busy today," Granados acknowledged, "but everyone has an hour once a week they could squeeze out of their schedule."

Also, she said, consider being a foster parent to, or perhaps adopting, one of these children.

Yes, you'll have to give them their medicine, take them to doctors and maybe face medical crises, but with today's medical protocols many children are healthy for long periods.

Yes, they have special needs. But they are no different than any other children in the love they give, or in the love they need.

Marian Wright Edelman is president of the Children's Defense Fund.

Health

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Q: What is Rett syndrome?

A: Rett Syndrome is a disabling developmental disease that strikes only females. Girls stop growing at around 18 months of age and

may develop mental retardation and display repetitive, involuntary movements involving their hands, feet and other parts of their body. They may experience problems walking, breathing and communicating.

Studies at the Children's Nutritional Research Center at Baylor College of Medicine found girls with Rett syndrome to be malnourished. Researchers also found a poor diet, not repetitive movements, led to the girls' altered energy balance and subsequent growth failure.

Girls with Rett Syndrome do not eat as much as healthy girls because it is hard for them to chew and swallow. In studies they were given large amounts of a high-quality liquid formula

through a button gastrostomy, a device placed directly into the stomach. All the girls gained weight and grew in height.

It is important for parents of girls with Rett Syndrome to seek out nutritional advice early on to combat the growth abnormalities.

Send questions to: Kids' Nutrition Q & A, USDA/ARS Children's Nutrition Research Center, One Baylor Plaza, Room 176B, Houston, TX 77030.

Money

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you change your mind later about bequests or wish to name a different executor, you may write a new holographic will with different provisions and destroy the old one.

However, you should be aware that self-made wills sometimes cause problems for heirs because of the wording or provisions that are left out.

You can buy a manual for the writing of wills that will help you with the legal language.

To be on the safe side, you might telephone or write to the office of the Attorney General in your state to confirm the legality of holographic wills.

An easier and safer option would be to engage a lawyer to draft a will for you that meets your particular needs while avoiding potential legal problems.

Achievement

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leaders — is to make sure that we build, as Powell told the inductees Saturday, "a community of adults who will help you achieve to the best of your ability."

That idea is the other pillar of the Campaign for African-American Achievement. We adults intend to help young people follow their natural inclinations to try to do their best.

The students that we've inducted into the Thurgood Marshall Achievers Society are evidence that many of our youth expect no less of themselves.

Foster Care

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experiences than bad ones being a foster child. She thinks foster care left her better off than a life with her mother would have. However, there have been tough times.

The worst, she said, was the death of a man she had bonded with. He had worked at a children's home where she had lived until the facility closed. The man, whom Runsewe still refers to as "my father", took a job caring for the elderly. The two maintained their ties until the man committed suicide, at age 35. Runsewe became depressed and her grades fell.

She has recovered and brought up her grades. Now a sophomore at Basic High, she plans to go to college. Runsewe lives at Regina Hall in Henderson. On her sixteenth birthday she will move into the home of a friend who is becoming a foster parent.

The high point of Runsewe's foster care

experience came a year ago when she became president of Foster Teens of Southern Nevada. The group meets twice monthly, observes parliamentary procedure and works toward educating people about and ensuring the rights of foster teens.

Robinson attends many of those meetings. In a recruitment pitch made at Friday's gathering, he said, "The children we serve require a lot of love, stability and guidance. They deserve comfortable and safe living environments."

"If there's anyone out there who has even considered becoming a foster parent," he said, "all they have to do is give us a call at our toll-free number: 1-888-4 A FAMILY (423-2659). It's not a commitment, it's just information sharing. We could mail them some materials about our program. They could call me personally."

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